Understanding and identifying ways to improve hospital-based cancer care and treatment for people with dementia: an ethnographic study

Abstract

Background: Providing cancer care and treatment for ageing populations with complicating comorbidities like dementia is a growing global challenge. This study aimed to examine the hospital-based cancer care and treatment challenges and support needs of people with dementia, and identify potential ways to address these.

Methods: Two-site ethnographic study in England involving semi-structured interviews, observations and accompanying conversations, and medical-record review. Participants (N=58) were people with dementia and comorbid cancer (n=17), informal caregivers (n=22) and hospital staff (n=19). Ethnographically informed thematic analysis was conducted.

Results: There was an accumulated complexity of living with both illnesses simultaneously. People with dementia and families could feel confused and uninformed due to difficulties understanding, retaining and using cancer information, which impacted their informed treatment decision-making. Dementia increased the complexity and burden of travelling to and navigating unfamiliar hospital environments, frequent lengthy periods of waiting in hospital, and self-managing symptoms and side-effects at home. Oncology staff were often working without the full picture, due to variable documenting of dementia in medical-records; dementia training was limited; and time and resource pressures impeded the highly-individualised, flexible cancer care required by people with dementia. Supportive family carers were crucial in enabling people with dementia to access, navigate and undergo cancer treatment and care

Conclusions: Dementia complicates cancer care in a range of ways accumulating across the cancer pathway. Our findings suggest there are several strategies and interventions, which we list here, with potential to improve cancer care and treatment for people with dementia and their families.

Introduction

Many older adults have two or more long-term conditions [1]. Multimorbidity is a growing challenge for health systems, which are typically organised around single diseases. Cancer has a high and increasing incidence globally, with incidence rates strongly related to age; in the UK, for example, more than a third of new cancer cases annually are in people aged 75+ [2,3]. Dementia is another prevalent long-term condition among older adults which, due to the nature of its symptoms and functional impact, is likely to make cancer care and treatment more complex [4,5]. Figures on the number of people with dementia and comorbid cancer (DCC) vary widely due to sampling and methodological heterogeneity [6], and will tend to underestimate due to dementia under-diagnosis [7]. Our recent analysis of UK primary-care data found 7.5% of cancer patients aged 75+ had dementia [8].

Research shows that people with dementia, compared to those without: (1) are more likely to be diagnosed with cancer at a later or unknown stage, during an emergency presentation, by chance and postmortem; (2) are less likely to receive treatment and guideline-concordant treatment, and are more likely to experience treatment complications and hospitalisations; and (3) have poorer survival [6,9,10].

To date, few qualitative studies have examined the cancer-related experiences and viewpoints of people with DCC, their carers and/or their clinical teams [e.g.11-13]. These studies highlight some of the challenges around cancer care for people with dementia, including dementia diagnosis not being disclosed and/or documented, assessing patient understanding, and dementia impeding recall of medical history and cancer information. These studies also show family caregivers are crucial in enabling people with dementia to access and undergo cancer treatment. Although mostly small and single-site, these studies are an important early step towards identifying possible ways to reduce dementia-related disparities in cancer care.

This qualitative study aimed to examine the challenges and support needs of people with DCC, their caregivers and clinicians, in relation to hospital-based cancer care and treatment, and to identify ways to address these.

Methods

Overview

Ethnographic study involving semi-structured interviews and observations. Participants were people with DCC, informal caregivers and staff recruited from National Health Service (NHS) Trusts and surrounding communities.

Patient and Public Involvement

A Lay Advisory Group of four people and relatives affected by DCC were involved in design, conduct, analysis, and dissemination of the study.

Setting

Two NHS-Trust sites providing hospital-based cancer services in the North of England; a large regional cancer centre providing specialist services (e.g. radiotherapy, rarer cancers), and one of a number of smaller cancer units in the region providing citywide services (e.g. chemotherapy). Many patients receive treatment at both their local unit and the centre.

Participants, sampling, and recruitment

People with DCC, caregivers, and staff were recruited according to the eligibility criteria in Table 1. Purposive sampling was used to recruit, as far as possible, participants with varied characteristics that may influence their experiences (e.g. cancer type, professional role). People with DCC and caregivers were identified and approached by staff during post-diagnostic appointments. Those who were interested discussed participation with a researcher, including eligibility for and preferences regarding data collection methods (i.e. participation in an interview or observations or both). The study was also advertised to people with DCC and carers via community groups and social media; interested people contacted the researchers for more information. Staff were approached directly by a researcher about study participation.

Data collection

Semi-structured interviews

Topic guides focused on experiences of cancer services, aspects of practice that worked well and areas of difficulty, and suggestions for ways cancer services could be improved for people with dementia. Participants were also asked to note key characteristics about themselves (Table 2). Interviews were conducted flexibly to permit and capitalise on the natural flow of the conversation. Interviews were conducted in private spaces (home, quiet hospital room), or occasionally by telephone, according to participant preference, and were audio-recorded and transcribed verbatim.

Observations, accompanying conversations and medical-record reviews

General observations of key clinical areas were undertaken to develop familiarity with the environments, and to sensitise the researchers to potentially important areas for exploration in individual participant observations. Observations of individual's with DCC and accompanying caregivers examined their experiences during one or more oncology appointments; observations focused on the actions of, and interactions between, patients, carers and staff, and on challenges and solutions and good practices in relation to care for people with DCC. Researchers talked to people with DCC, carers and/or staff during and after appointments to further explore what had been observed. Observational notes were handwritten and type-up into detailed fieldnotes. Medical-records of observed individuals were reviewed and included in the fieldnotes.

Data Analysis

Data analysis ran alongside and informed subsequent data collection. Ethnographically informed thematic analysis, following an iterative process, explored the content and patterns in the data via

triangulation across data sources [14]. A sample of interview and observation transcripts were read and independently coded at a line/paragraph level (by RK,AG,CS,FC); these initial codes were grouped into broader areas to develop a coding framework, which was developed and refined as analysis progressed, and in collaboration with two members of the Lay Advisory Group. Staff interviews were initially analysed separately to those with people with DCC and carers and the fieldnotes, before the developed themes were compared and contrasted to produce definitive themes, which were finalised through review and discussion.

Ethics

Approval was obtained from the Yorkshire & The Humber Bradford-Leeds Research Ethics Committee (ref:18/YH/0145). All participants provided informed consent. When people with dementia lacked capacity to consent, a personal consultee (relative) was appointed to provide advice on their wishes regarding participation (Mental Capacity Act, 2005). Staff were made aware of the study before observational data collection commenced, and verbal consent was obtained from staff present during individual observations.

Results

Participants

Participant numbers and characteristics are summarised in Table 2.

Data collection

We conducted 37 interviews involving 53 participants (12 people with DCC, 22 caregivers, 19 staff), ranging from 9-194 minutes, according to participants' preferences and communication abilities. We conducted individual observations of 10 people with DCC, which included one or more of their caregivers. General and individual observations totalled 46.25 hours and included consultations, treatment, scans and tests. Data were collected (by RK & AG) in 2018-2019.

Key findings

Five themes, unified by an overarching-theme of *accumulated complexity*, were developed to capture the range of ways in which cancer care was complicated by comorbid dementia. The data were analysed as a whole, with interview and observational data from the different participant groups and sites contributing to the development of all themes. This paper presents a summary of all themes and focuses in detail on the resulting recommendations for practice; separate papers provide a thorough exploration of selected individual themes with broader illustrative data [15,16].

There was an *accumulated complexity* of living with both illnesses simultaneously. For people with DCC and their families, dementia increased the complexity and burden of cancer treatment decision-making; practically and emotionally navigating cancer care; and self-managing symptoms and side-effects at home. For oncology staff, dementia and associated social care needs added complexity across the

cancer pathway, to treatment decision-making; managing people's psychosocial needs and behaviours in clinic; and monitoring symptoms and side-effects outside hospital.

Working without the full picture

Staff were not always aware of dementia, often needing to proactively search medical-records to establish a dementia diagnosis, which was not always recorded, and was seldom documented in an easily-accessible and consistent way. Staff noted limitations in their dementia knowledge and training:

> *Consultant pulls face at idea they don't see anyone [with dementia], feels they're not spotting it*
>
> Fieldnotes: general observations

> *One man recently…he had a diagnosis of dementia. And it wasn't until we saw his medication history that he was on is it Memantine?* [drug used to treat dementia]
>
> Prostate Clinical Nurse Specialist (L007)

> I: *You said that the cancer care staff aren't aware of the memory problems?*
>
> P1: *Because the sticker never went on* [to flag dementia on medical-record]…*they*
>
> *never put the sticker on and that would have only helped them*
>
> Sister of lady with DCC (L0019)

> *We are all technically 'Dementia Friends'* [dementia information sessions designed for the general public]*, but we don't have any revalidated training…there's no further training that we do. I'm really limited in what I know*
>
> Radiographer (L0028)

People with DCC could feel confused and uninformed as they struggled to understand and retain information about their cancer diagnosis and treatment. There were times limited understanding could reduce worry for people with DCC, although caregivers then carried the emotional burden alone. Caregivers could similarly find complex cancer information difficult to understand:

> Nurse: call up on the Wednesday, get your bloods done and check they're okay. Then if they're okay come on the Thursday, but if they're not okay don't come otherwise it's a long journey.
> Amanda: thanks.
> Nurse walked out, Amanda turned to me: I don't have a clue what she means

Fieldnotes: lady with DCC (B010)

He said no, have we been to hospital? Yes, we've just spent four hours in hospital. Do you not have any recollection? No, I thought we'd been shopping…I suppose we worried for him

Son of gentleman with DCC (C004)

If they had explained it better I probably would have got him treatment

Wife of gentleman with DCC (L0036)

Difficulty and diffusion of treatment decision-making

Dementia impacted on the perceived appropriateness of treatments. Concerns were raised that people with memory loss could suffer emotional distress each time they re-received the news they had cancer or re-observed changes to their body due to treatments. Some people with DCC were considered unlikely to cope psychosocially with the demands of treatment:

If they've had for instance, a breast removed, they may have forgotten why that's been done. They may feel that they've been mutilated against their will

Consultant Surgeon (L0041)

P2: *We were frightened with the operation if she went on to a surgical ward…*

P1: *Yeah, not a dementia ward.*

P2: *…them pushing the trolley up and, 'do you want any breakfast?' and it'd be 'no', because she won't eat, 'do you want a drink?', 'no', we just had nightmares didn't we, thinking what's she going to do just laid there*

Daughters of lady with DCC (B013-14)

She says that chemotherapy would have been a 'no no', commenting on having to sit still all that time (so I wonder if she has muddled that up with radiotherapy)

Fieldnotes: lady with DCC and daughter (L0010-11)

Decision-making required time and considerable effort to ascertain the extent to which a person with DCC could understand and communicate their wishes and thus be as involved as possible. Relatives

found treatment decision-making stressful, especially if there were disagreements between stakeholders:

> *She would often say, I don't even know if mum really knows what we're doing here…there were a lot of consultations with her daughter before she got to surgery, a lot*
>
> Breast Care Nurse Specialist (B007)

> *They might push to say, well she should have the operation…when you've got family, everyone has got an opinion, but they don't know the whole picture*
>
> Daughter of lady with DCC (L0010)

Balancing person versus process

People with DCC often required individualised, flexible care to understand and undergo cancer treatment. Examples of this included recognition of and response to the individual needs of the person and their family, tailored communication including simplified and visual approaches, and continuity in staff, routines and environments:

> *Dementia patients we've had, have a lot of hospital visits. Sometimes, it's too much. It's too much. So, we do tend to do a lot over the phone. Sort of, the cancer care and reviews*
>
> Lung Clinical Nurse Specialist (B005)

> P1: *a Doctor, Professor, you think well you've got to take your dictionary in with you, but he came down to our level…*
>
> P2: *And my level*
>
> Lady with DCC and granddaughter (L004-05)

> *She'd often be a lot more agitated if she was up early, so we did things later in the day*
>
> Breast Nurse Specialist (B007)

Observations highlighted aspects of oncology care that make providing highly person-centred care a challenge: a large volume of patients tightly scheduled, very precise and protocol-driven treatments, and involvement of multiple departments and staff, often located at different sites. Factors which shifted the balance from person to process focused working included the degree to which dementia was

recognised and understood by oncology staff, workload and staffing pressures, and the extent to which individual staff felt able to deliver a dementia-tailored approach:

> *It's about [e.g. cancer waiting time] targets, targets, targets. But there's certain people that targets don't work for where it's about time and patience and effort*
>
> Lung Clinical Nurse Specialist (B006)

> *Dementia-friendly, that was our main concern. Some of the doctors, him that removed me from that room, he doesn't have that personal touch, yes. He didn't know that she had dementia*
>
> Sister of lady with DCC (L0019)

> *Approach is standard appointment times regardless of additional needs. Paediatrics appears to be an exception where additional time is accepted.*
>
> Fieldnotes: general observations

> *It'd be nice if the system would say, actually, Jane's got dementia, she needs a two hour, an hour slot, and if we had the capacity to do that, we don't*
>
> Consultant Oncologist (L0043)

Burden of navigating cancer care

Dementia alongside cancer complicated navigation of the multiple oncology appointments, treatment settings and rounds, and journeys to and from the hospital. Observations highlighted challenges of the hospital environment likely to be amplified for people with dementia, including large, busy, and unfamiliar buildings, and frequent lengthy periods of waiting. General observations included paediatric areas which, in contrast to the adult spaces, were better designed to mitigate the difficulties of hospital navigation and waiting:

> Maeve, who has come to hospital alone, tells the doctor forlornly she has been 'lost all morning', referring to a 'problem with the transport place'. She adds 'I didn't know where I was', becoming tearful as she is 'worried about where my husband is' and 'getting home'
>
> Fieldnotes: lady with DCC (L001)

There's like little, like aprons and stuff you can get and stuff for them to just [i.e. sensory activities for people with dementia]*…keep people occupied. Because it's, they are you know, waiting…we've got all these patients to treat, but actually waiting for patients is a problem*

Patient information and support advanced practitioner, radiotherapy (L0042)

Children's department, there are things to look at and play with, colour and decorations, photos and names of staff on the wall…stark contrast to plainer clinical areas elsewhere devoid of much to look at or do.

Fieldnotes: general observations

People with DCC and their family were not only navigating cancer care, but simultaneously navigating care for dementia and often also other comorbidities. This meant a greater total burden of medical information, appointments and events to practically and emotionally navigate. Multiple care pathways created the potential for clashes between care events, and necessitated cancer clinicians to communicate with other professionals, which happened to varying degrees:

I: *So having to deal with diabetes, cancer diagnosis and memory problems?*

P1: *Yeah!*

P2: *And she were going through hip problems and having to go for injections for the hips as well… and physiotherapy after that, and it got a bit*

P1: *Overwhelming*

Lady with DCC and husband (B001-02)

I found it quite difficult, because there did seem to be a lot of people because a lot of the care is sectioned off for example the district nurses don't do incontinence. And the carers at first wouldn't do colostomy bags

Wife of gentleman with DCC (C002)

Reliance on supportive family networks

Relatives played a crucial role in supporting people with DCC to access, navigate and undergo cancer treatment and care. For example, families frequently organised and attended appointments and treatment sessions; retained, relayed and explained cancer and treatment information to the person with DCC and other stakeholders; provided emotional support and reassurance during treatments; and managed, monitored and reported symptoms and side-effects:

Lady from a care home [who appears to have dementia] comes to clinic alone, so difficult for doctor to get any information, lady is muddling-up current and previous problems and unable to explain her situation.

Fieldnotes: general observations

Can't see how you would ever be able to treat someone with dementia, if you didn't have, sort of, support from either an advocate, or a carer, or a family member. Because if these patients can't verbalise any problems, then it's dangerous

Lung Clinical Nurse Specialist (B005)

She would keep still because he [her husband] *kept telling her to stay still* [during radiotherapy]. *She obviously remembered who he was as opposed to us*

Senior Radiographer (L0022)

Nurse and Jane agreed it was easier for the medical supplies to go to Jane's house… Nurse held out the [catheter] tube to Graham and asked 'do you want to have a go?' Graham handed the tube straight to Jane

Fieldnotes: gentleman with DCC and daughter (L0039-40)

When there was no family network who could provide support, it was unclear who should assume responsibility for the enabling role usually played by relatives. People with DCC attending hospital alone relied on the goodwill of oncology staff to provide support, due to an absence of available services to fill this gap:

The lady was wandering about so what we try and do is either get one of us, or a student, to sit with her…whoever's available

Macmillan support co-ordinator (L0044)

There is no one to support this sort of thing…there was some memory nurse input, so we requested that they provided some support around escorting. But again, they didn't seem to see it was their role

Social worker (L0013)

Discussion

This is one of the first qualitative studies to examine the cancer-related experiences of people with dementia, their families, and clinical teams. The findings corroborate and extend previous work in this area; provide explanatory insights into dementia-related cancer disparities; and indicate ways to improve oncology care and treatment for people with dementia.

This study corroborates earlier findings from a handful of small single-site studies, strengthening their validity and indicating common relevance across sites. Findings consistent with those of previous work [e.g.11-13] include: difficulties identifying dementia and limited documentation in oncology medical-records; unmet dementia training needs amongst oncology staff; heightened challenges for people with DCC and caregivers around understanding and using cancer and treatment information; the complicating impact of dementia on treatment decision-making; and the crucial enabling role of family caregivers.

Our findings highlight how dementia complicates the practicalities of attending oncology appointments due to 'dementia-unfriendly' features of the organisational and built hospital environment. Albeit touched-upon by Witham et al. [12], this issue was not raised in the previous studies in this area, although is well-covered in the wider dementia literature [17]. It is worth noting, however, as our findings show that concerns about how people with DCC will cope in hospital settings influence treatment decision-making, and because dementia-friendly environment research and practice implementation has mainly focused on inpatient care [e.g.18], whereas oncology is predominantly outpatient-based. As cancer care often involves multiple lengthy appointments, improving the dementia-friendly organisation and design of oncology departments, and outpatient settings generally, is a worthwhile area for future research.

Evident in the overarching-theme of *accumulated complexity*, and particularly captured by the *burden of navigating* theme, is the greater total burden of 'illness work' (e.g. medical appointments) upon this cancer patient group owing to them simultaneously managing care for dementia, and often other illnesses prevalently comorbid with dementia [19]. That cancer care and treatment come atop existing illness work for people with DCC is not something discussed in previous studies in this area. It is crucial, however, to be cognisant of and responsive to the cumulative burden upon people with DCC, as high treatment-burden is associated with lower quality-of-life and treatment adherence, which can lead to poorer clinical outcomes and hospitalisations [20].

Although previous work has similarly underscored the crucial role of family caregivers [11-13], it does not speak to what happens when there is no supportive family network. Our study found that people with DCC attending hospital alone were reliant for escorting and support on the goodwill of busy oncology staff, who struggled to identify and enlist assistance from other professionals or services. Future research should explore the feasibility of addressing this support gap with patient navigators, who are increasingly used in the US and Canada to help reduce cancer inequalities [21].

Based on our findings, Table 3 summarises key recommendations for oncology hospital services and staff to improve cancer care and treatment for people with dementia and their families. To our

knowledge, this is the current most comprehensive single list of such recommendations and accompanying potential strategies and interventions for their implementation. Though some strategies require longer-term planning and financing by service managers, many are implementable promptly by individual staff at minimal cost. Not all oncology departments will be able to implement all improvement suggestions, but they could use Table 3 to identify and select strategies which are locally feasible in the short, medium, and longer-term.

There are interventions we have not included in Table 3, but which have beneficial potential and are worthwhile areas for future research. First, in relation to the previously discussed high treatment-burden upon many people with DCC, research has recently developed conversation-aid tools to help clinicians assess and discuss treatment-burden, and thus take actions to improve illness-workloads for highly-burdened patients [e.g.22]. Evidence for these tools is still in-progress, but they may assist oncology staff in understanding an individual's holistic 'medical and social landscape' and thus providing the individualised care needed by people with DCC. Second, in relation to the issue of *working without the full picture*, a sizable literature shows benefits of audio-recording oncology consultations upon knowledge, information recall, decision-making factors and anxiety [23], and apps have been developed especially for this purpose (e.g. *SecondEars* [24]). Audio-recording consultations could help to make cancer information more accessible, shareable, and useable for family caregivers; recordings may also be directly useful to people with DCC, though this would need to be examined in future work. Third, given their heightened hospital navigation and travel challenges, people with DCC and their caregivers are a group who may gain high benefit from, and could be considered high-priority for, mobile cancer services. Several NHS-Trusts operate mobile units which administer chemotherapy and supportive treatments close to home [25], and research shows that patients find mobile treatment less stressful and requiring much shorter waiting times [26]. However, evaluative studies of mobile-units do not appear to have included people with DCC; future work should establish to what extent people with DCC do, or could, beneficially use this service where available.

Strengths of this study include data collection from multiple perspectives and sources across two sites, and inclusion of people with dementia of varying types and severity. Limitations include recruitment from one English region and limited diversity among participants with DCC regarding cancer type and treatments (predominance of lung cancer and experiences of radiotherapy) and residence (living at home). Participants were also near-entirely White British. It is likely a very low proportion of study-eligible patients were from Black, Asian, and Minority Ethnic (BAME) groups, given that Alzheimer's Society report just 3% of people with dementia are from BAME communities (25,000 people UK-wide) [27], and only a subgroup of these will also have cancer. Previous studies in this area [11-13] do not report the ethnic profile of their samples, possibly indicating low representation of BAME groups in these studies also. Further work in this area would ideally include a qualitative study with a BAME sample to establish to what extent the collective findings thus far are generalisable, and to identify any DCC-related challenges and support needs distinct to BAME groups. However, given the low numbers of BAME people with DCC, such a study would require multi-site or even UK-wide recruitment.

Conclusions

Dementia complicates cancer care in a range of ways accumulating across the cancer pathway. Our findings suggest there are many practically-oriented strategies and interventions, which we list here, with potential to improve cancer care and treatment for people with dementia and their families.

Conflicts of interest

None

Data statement

Data may be made available on reasonable request to the corresponding author for the purposes of further research.

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Table 1: Participant eligibility criteria

People with dementia and comorbid cancer (DCC)	- Confirmed or suspected dementia indicated by a FAST (Functional Assessment Staging) score 4+ - Receiving National Health Service (NHS) care for any type of cancer, or had within the last 2 years - Received NHS cancer care since the onset of their dementia Participation in an interview: ability to recall and discuss their care experiences Participation in observations: currently receiving care at a participating site
Informal caregivers	- Current or recent (last 3 years) experience of caring for a person with DCC - Caring includes having attended NHS hospital cancer services with the person with DCC - Not recently bereaved (within the last 3 months)
Staff	- Employed at a participating site - Recent experience of providing cancer (or related) care to people with dementia

Table 2: Participant numbers and characteristics (N=58)

Characteristics	n (%)
Participants with dementia and comorbid cancer (n= 17)	
Female, n (%)	10 (59)
Cancer type, n (%)	
Lung	8 (47)
Prostate	4 (24)
Breast	1 (6)
Gastrointestinal	1 (6)
Other	3 (18)
Ethnicity	
White British	16 (94)
Hispanic	1 (6)
Age, mean (range) (n=13)	75 (45 – 88)
Family caregivers (n=22)	
Female, n (%)	14 (64)
Relationship to patient	
Child	12 (55)
Spouse	7 (32)
Sibling	2 (9)
Grandchild	1 (5)
Staff (n=19)	
Female, n (%)	14 (74)
Oncology role worked in	
Radiotherapy dept	7 (37)
Lung cancer clinic	6 (32)
Breast cancer clinic	3 (16)
Prostate cancer clinic	1 (5)
Other	2 (11)
Staff role	
Nurse	8 (42)
Radiographer	7 (37)
Consultant	2 (11)
Social worker	1 (5)
Patient transport officer	1 (5)

Table 3: Recommendations and potential strategies and interventions for oncology hospital departments and staff to improve cancer care and treatment for people with dementia and their families

Recommendations	**Suggestions for implementation**
Improved dementia awareness, identification, and documentation	
Ask about memory problems at an initial appointment (and periodic follow-ups)	Add a question about possible memory problems to existing assessment and review forms Include a follow-up question(s) about the functional impact of any memory problems, especially as relates to undergoing cancer treatments
Record dementia and associated needs accessibly in oncology medical-records	Create designated space in the electronic medical-record to record dementia (or note memory problems) and related needs and support in place Tag electronic medical-records with a flag/icon/pop-up which alerts staff accessing the record that the patient has dementia (or memory problems)
Providing staff with training and tools to support person-centred dementia care	
Ensure oncology staff have access to practical information and training on dementia	Collate information in a shared-drive e.g. details of local referral pathways for memory assessment and support, relevant clinical guidance (e.g. [28]) Promote staff access to high-quality dementia training tailored to their role (e.g. Macmillan dementia training especially for oncology staff), to increase staff knowledge and confidence, and reduce the potential for dementia stigma
Use simple tools to support discussion of dementia and related needs	For example, the simple *This is Me* leaflet from Alzheimer's Society can facilitate collection of personal information key to caring well for someone with dementia
Support for people to attend hospital for cancer treatment and care	
Offer flexibility in timing and location of appointments where possible	Conduct some appointments by telephone (e.g. follow-ups) Schedule as best suits the person with dementia (e.g. always afternoon slots) Longer slots for key consultations and some treatment sessions (e.g. radiotherapy)
Give consistency of people and place where possible	Provide the same clinician(s) and treatment seat/room where possible
Mitigate hospital travel challenges	Ensure people with dementia are asked about requirements for an escort seat on patient transport at the time of booking Broaden support at hospital entrances (e.g. volunteer staff) to explicitly include waiting with people with dementia while their carer parks/fetches the car
Providing a supportive physical environment	
Enhance oncology departments to be more dementia-friendly	Draw on existing guidance for hospitals [29] e.g. clearer signs for toilets and exits; clocks and calendars on walls; colour-coding to distinguish areas Have dementia-friendly books and activities (memory boxes) in waiting areas
Make the environment familiar before treatment starts	Provide leaflets with colour photos (or YouTube video) of the depts and equipment Offer pre-treatment visits (e.g. some radiotherapy depts run regular information sessions for new patients which include a tour and demo of the equipment)
Supporting treatment decision-making	
Provide accessible written summaries of key	Give short simple bullet-points

information and discussions	Use any idiosyncratic terms used by the person with dementia (e.g. Big Machine) Include visuals to explain things (e.g. have paper in consulting rooms pre-printed with a body outline for drawing information about tumour size and location)
Enable easy communication with other key professionals	Geriatricians in the Trust, for example: invite them to relevant dept meetings, establish a communication pathway for seeking their input into care decisions
Inclusion and support of families (where desired by patients and carers)	
Include carers in provision and discussion of care information	Send a nominated family member copies of hospital letters Incorporate the views of family when discussing treatment and care options
Permit carers to be present during treatment	Radiotherapy, for example: allow carers to help settle patients on the table, and then to use the tannoy/intercom to help instruct and reassure during treatment
Recognise and ease the emotional and physical burden upon carers	Ask carers how they are coping and consider their needs (e.g. getting time off work, own health problems) in care planning and support provision Help carers with managing treatment side-effects (e.g. catheters, pain) by giving ample practical information, and arranging needed support (e.g. district nurses) Signpost carers to dementia and comorbid cancer specific support resources e.g. - Macmillan's *Cancer and Dementia*: *a Guide for Carers* booklet - Alzheimer's Society's cancer section of their carers online support forum [30]